

Disease in History: Frames and Framers

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MEDICINE, AN OFTEN-QUOTED HIPPOCRATIC teaching explains, “consists in three things—the disease, the patient, and the physician.” When I teach an introductory course in the history of medicine, I always begin with disease. There has never been a time that humankind has not suffered from sickness, and the physician’s specialized social role has developed in response to it. Even when they assume the guise of priests or shamans, doctors are by definition individuals presumed to have special knowledge or skills that allow them to treat men and women experiencing pain or unable to work and fulfill family obligations.

But “disease” is an elusive entity. It is particularly difficult to explain to college students who generally see it in simple pathophysiologic terms; the relation between somatic mechanism and social consequence seems clear and unambiguous to even the most thoughtful undergraduates. When pressed for a definition, their responses tend to be one-dimensional: “something amiss in the body,” one typical example of the genre explains, “that causes pain or disability.”

The reality is obviously a good deal more complex. Disease is at once a biological event, a generation-specific repertoire of verbal constructs reflecting medicine’s intellectual and institutional history, an aspect of and potential legitimation for public policy, a potentially defining element of social role, a sanction for cultural norms, and a structuring element in doctor/patient interactions. In some ways dis-

ease does not exist until we have agreed that it does—by perceiving, naming, and responding to it (Rosenberg 1986).

Disease can, of course, be construed in one of its primary aspects as the working out of a pathological process. As such it exists in animals—who presumably do not socially construct their ailments and negotiate attitudinal responses to sufferers—but who do experience pain and impairment of function. And one can cite instances of human disease that existed in a purely biological sense—certain inborn errors of metabolism, for example—before their existence was disclosed by an increasingly knowledgeable biomedical community. Nevertheless, it is fair to say that in our culture a disease does not exist as a social phenomenon until we agree that it does. And those acts of agreement have during the past century become increasingly central to social as well as medical thought (assuming the two can in some useful ways be distinguished). Many physicians and laypersons have chosen, for example, to label certain behaviors as disease even when a somatic basis remains unclear—and possibly non-existent: one can cite the instances of alcoholism, homosexuality, or “hyperactivity.” As we are well aware, the status of homosexuality as “disease” has been in recent years an object of explicit and instructive contention (Bayer 1981).

Much has been written during the past two decades about the social construction of illness. But in an important sense this is no more than a tautology—a specialized restatement of the truism that men and women construct themselves culturally. Every aspect of an individual’s social identity is constructed—and thus also is disease. Although this social-constructionist position has lost much of its novelty during the past decade, it still serves to remind us of some important things. Perhaps most significant is the fact that medical thought and practice is rarely free of social and cultural constraint, even in matters seemingly technical. The explanation of sickness is too sensitive—socially and emotionally—for it to be a value-free enterprise. It is no accident that several generations of anthropologists have assiduously concerned themselves with disease concepts in a variety of non-Western cultures; agreed-upon etiologies at once incorporate and sanction a society’s fundamental ways of organizing its world. Medicine in the contemporary West is by no means divorced from such affinities.

Some of those constraints reflect values, attitudes, and status relationships in the larger culture (of which physicians, like their pa-

tients are part). But medicine, like the scientific disciplines to which it has been so closely linked in the past century, is itself a social system; even those technical aspects of medicine seemingly little subject to the importunate demands of cultural assumption are shaped in part by the shared intellectual worlds and institutional structures of particular communities of scientists and physicians. These realities all interact to play a role in the process through which we formulate and agree upon definitions of disease. In this sense, the term "social history of medicine" is as tautological as that of the "social construction" of disease; every aspect of medicine's history is necessarily "social"—that acted out in laboratory or library as well as at the bedside.

In the following pages I have, in fact, avoided the term social construction. I felt it has tended to overemphasize functionalist ends and the degree of arbitrariness inherent in the negotiations that result in accepted disease pictures. It has focused, in addition, on a handful of socially resonant diagnoses—hysteria, chlorosis, neurasthenia, and homosexuality, for example. It invokes, moreover, a particular style of cultural criticism and particular moment in time. I have chosen instead to use the less programmatically charged metaphor "frame" rather than "construct" to describe the fashioning of explanatory schemes for particular diseases.

During the past two decades, social scientists, historians, and physicians have shown a growing interest in disease and its history; the attention paid social-constructivist views of disease is one aspect of a multifaceted scholarly concern. The response to AIDS in recent years has only added impetus to and focused public attention on an already thriving academic enterprise.

The recent interest in the history of disease has reflected and incorporated a number of separate—and not always consistent—trends. One is the emphasis among professional historians on social history and the experience of ordinary men and women. Pregnancy and childbirth, for example, like epidemic disease have become an accepted part of the standard historical canon. A second focus of interest in disease centers on public health policy and a linked concern with explanation of the demographic transition; how much credit should go to specific medical interventions for the decline in morbidity and lengthening life spans, and how much to changed economic and social circumstances? The name of Thomas McKeown has been closely associated with revitalizing this century-old debate (McKeown and Re-

cord 1962; McKeown 1976a, 1976b). Third, is the rebirth of what might be called a new materialism in the form of an ecological vision of history in which disease plays a key role—as, for example, in the Spanish Conquest of Central and South America (Crosby 1972, 1986; McNeill 1976). Fourth, has been the influence of demography among a quantitatively oriented generation of historians and of history among a growing number of demographers. The study of individual disease provides one strategy for ascertaining the mechanisms underlying aggregate change in morbidity and mortality figures. Finally, and perhaps most widely influential, has been the growth of interest in the way disease definitions and hypothetical etiologies can serve as a tool of social control. Logically enough, such views have often been associated with an emphasis on the social construction of disease (see, among numerous examples, Wright and Treacher 1982; Figlio 1978). Such interpretations are one aspect of a more general interest in the relations among knowledge, the professions, and social power. Within such formulations, physicians are construed as articulators and agents of a broader hegemonic enterprise—the “medicalization” of society one aspect of an oppressive ideological system.

What is often lost sight of in each of these emphases—and in the aggregate in all—is the process of disease definition itself, and, second, the consequences of those definitions once agreed upon in the lives of individuals, in the making and discussion of social policy, and in the structuring of medical care. We have, in general, failed to focus on that nexus between biological event, its perception by patient and practitioner, and the collective effort to make cognitive and policy sense out of those perceptions. Yet, this process of recognition and rationalization is a significant problem in itself, one that transcends any single generation's time-bound effort to shape satisfactory conceptual frames for those biological phenomenon it regards as of special concern. Nor can it while men and women seek cure and understanding of their ills and physicians seek the reputation that comes with innovation and publication. Where an underlying pathophysiologic basis for a putative disease remains problematic—as in alcoholism for example—we have another sort of framemaking, but one that nevertheless reflects in its style the plausibility and prestige of an unambiguously somatic, mechanism-oriented model of disease. This reductionist tendency has been logically and historically tied to another characteristic of our thinking about disease—and that is its specificity.

In our culture, its existence as *specific* entity is a fundamental aspect of the intellectual and moral legitimacy of disease. If it is not specific, it is not a disease and a sufferer not entitled to the sympathy—and in recent decades often the reimbursement—connected with an agreed-upon diagnosis.

Framing Disease

Disease begins with perceived and often physically manifest symptoms. In all those centuries before the nineteenth, physicians and their patients had to try to make sense out of these symptoms—imposing an array of speculative mechanisms on the otherwise opaque body.

The condition called “dropsy” provides an excellent case in point. As Steven Peitzman (1989) emphasizes in recounting Samuel Johnson’s experience of sickness, this was a familiar and ominous condition—one understood in parallel ways by patient and practitioner. The felt and visible edema or “dropsy” implied fundamental internal dysfunction—but the precise nature of that dysfunction could hardly be determined in the eighteenth century. Nor could edema arising from a variety of sources be disaggregated by contemporary clinical skills. Some dropsies seemed to respond to one diuretic or another, for example, some temporarily, some with more lasting results (as in the case of digitalis). “Dropsy” meant something very concrete to late eighteenth- and early nineteenth-century practitioners and their patients alike. It is hardly surprising that physicians and educated laypersons should have employed the conceptual tools of a traditional pathology with which to frame this familiar yet frightening clinical phenomenon. Dropsy seemed to fit neatly into neohumoral models of pathology with their emphasis on balance and intake and outgo; the clinical reality of dropsy, with its accumulation of fluids and responsiveness to diuretics, seemed, in fact, to justify this speculative model, just as the model helped frame the clinical reality.

But in the course of two centuries since Samuel Johnson’s grim illness, that phenomenon called dropsy came to be understood in fundamentally different ways. For example, Richard Bright distinguished that portion of this symptom attributable to kidney dysfunction in the 1820s; he was able to associate a clinical picture during life with post-mortem appearances and with chemical changes in the urine. Later in the nineteenth and into the twentieth century,

clinicians defined and redefined that agreed-upon picture of Bright's disease. Microscopic pathology focused on the fine structure of the lesions characteristically associated with renal disease. In the twentieth century, the interests of a physiologically oriented and self-consciously scientific generation of nephrologists turned to functional criteria—supplanting the anatomical, lesion-oriented conception of the disease so influential in previous decades. Finally, Peitzman argues, we have in the past two decades created a very different *de facto* framework around renal dialysis; most patients never become dropsical at all and their experience is that of dialysis and not the illness dialysis is meant to avert. End-stage renal disease (ESRD) has a fundamentally administrative meaning today; it is an automatic trigger for reimbursing providers of dialysis. Yet, ESRD is not simply an arbitrary neologism spawned by bureaucratic necessity—but at one remove the reflection of a real pathology interacting with a specific technology in specific social and political circumstances. The evolving framework of pathological assumption explaining and describing "Bright's disease" has been gradually integrated and reintegrated into a series of differently focused explanatory frameworks for the same clinical pictures (for the ability of medicine to alter the course of chronic renal disease remained, as Peitzman emphasizes, minor until the dialysis era). It is precisely this process of definition and redefinition that demands scholarly attention; it tells us a great deal about the evolution of medical thought and practice. In another dimension it provides access into the experience of ordinary people during the past century.

If the materials available for framing disease can change, so can those biological phenomena which demand framing. Peter English (1989) reminds us of this complex and elusive aspect of disease history. Rheumatic fever might well, he argues, not have existed in its nineteenth-century clinical form much before its perceived emergence during that century of enormous social change. Yet as he also reminds us, institutions and ideas in medicine were evolving at the same time. The greater likelihood of hospitalization, for example, and the prominence of hospital-based studies in discerning and defining clinical entities almost certainly played a role in framing what physicians came to call rheumatic fever, with its characteristic—and attention-focusing—incidence of cardiac involvement. English is equally well aware that the conceptual and technical tools to correlate systematically appearances after death with symptoms in life did not really exist

before the beginning of the nineteenth century. This timing constitutes an intricate and intractable, yet highly significant, dilemma. How does one make sense of this interactive negotiation over time, this framing of pathophysiologic reality in which the tools of the framer and the picture to be framed may well have *both* been changing (and in which the relation between *all* instances of symptom-producing interactions between humans and streptococci and that portion actually identified as rheumatic fever remained unclear)?

The history of that clinical entity called rheumatic fever illustrates not only a conceptual evolution, but a necessarily related and parallel evolution in representation. The first clinical descriptions were presented in the discursive narrative form of individual doctor-patient interactions (which came to include a revelatory coda in the form of post-mortem results) so characteristic of the late eighteenth and early nineteenth century. By mid-century, the disease was being represented in the form of numerical aggregates summarizing hospital experience. Walter B. Cheadles' depiction of rheumatic fever as a linked cluster of symptom configurations constituted still another step in the evolution of efforts to represent—and in representing to legitimate—this elusive clinical experience. In retrospect it is hardly surprising that Cheadle's work should have appealed to contemporary practitioners. It provided a viable—if schematic—compromise between a unified yet abstract clinical entity and its protean manifestations in hospital ward and consulting room. In more recent generations, of course, laboratory findings became central to a new style of conceptualizing and representing this elusive ailment.

As these studies of renal disease and rheumatic fever emphasize, physicians have always been dependent on time-bound intellectual tools and institutional arrangements in seeking to find and represent patterns in the bewildering diversity of clinical phenomena. For a physician in the late eighteenth and early nineteenth centuries, as we have suggested, neohumoral models were particularly important—and used to rationalize such therapeutic measures as bleeding, purging, and the lavish use of diuretics. With the emergence of pathological anatomy in the early nineteenth century, hypothetical frameworks for disease were increasingly fashioned in terms of specific lesions or characteristic functional changes that would, if not modified, produce lesions over time. The germ theory created another kind of framework that could be used to impose a more firmly based taxonomic order

on elusive configurations of clinical symptoms and post-mortem appearances. It seemed that it would be only a matter of time before physicians understood all those mysterious ills that had puzzled their professional predecessors for millennia; the relevant pathogenic microorganisms need only be found and their physiological or biochemical effects understood. This was an era, as is well known, in which energetic—and sometimes overly credulous or ambitious—physicians “discovered” microorganisms responsible for almost every ill known to humankind.

In his discussion of parasitology, John Farley (1989) illustrates the more general truth that particular framing options were not equally available to would-be framers. The parasite model seemed in the first half of the nineteenth century little relevant to most human ills. The study of parasites was segregated intellectually—and thus in the formative decades of the germ theory the possibility of creating a unified etiological theory was ignored. In the late nineteenth and early twentieth centuries, parasitology was institutionally segregated in schools of tropical medicine, public health, and agriculture (paralleling the marginalization of tropical medicine from the central foci of mid-twentieth-century medicine in Europe, England, and North America). Intellectual and institutional history defined, that is, certain options as immediately accessible, defining others as relatively unavailable to physicians and biologists as they sought understanding of particular ills. The slowness to generalize models of parasitism to human disease was as much a contingent aspect of a particular history as was the often unthinking and mechanical application of other models—most conspicuously in the parallel history of the bacteriological theory of infectious disease.

But the framing of disease is in another of its dimensions rooted in the necessities of care and the specific biological character of particular ailments. Tuberculosis provides a useful example. The most important single cause of death (and an important factor impoverishing families) in the nineteenth century, consumption provided a challenge to policy makers and welfare authorities as well as to physicians. Ubiquitous and discouraging, it constituted a problem of a very different kind than, let us say, cholera, yellow fever, or typhoid. The course of the disease was unpredictable and the great majority of victims deteriorated gradually, hoping all the while to live and work a normal life as long as they could; when that became impossible

they needed food, warmth, and care. Many hospitals would not admit them as incurable; most families could ill afford to care for wives, husbands, and children when their symptoms became well defined (Bates 1988). Romantic glorification of the consumptive was a rarefied and largely literary phenomenon.

With Koch's demonstration of the tubercule bacillus (1882) and the growing faith in sanitarium treatment, perceived options changed. Yet, the situation was still a difficult one. Proving the contagiousity of consumption posed a question; it did not provide answers. These had to come from public authorities and private charity. Only gradually did these sources provide institutional care for the poor as well as the prosperous—and only gradually did the medical and nursing professions find an appropriate framework within which to organize their own response. Even the apparent need to identify and isolate sources of contagion did not lead to immediate sequestration of active cases. Some physicians opposed such compulsory measures and then refused to cooperate with notification requirements when imposed (Fox 1975). State and local governments were slow to provide the enormous sums such a policy implied. Most physicians did not care to treat patients who showed little tendency to recover—and those with more attractive options avoided the isolated life of the tuberculosis sanitarium. Patients, on the other hand, were ordinarily loath to enter treatment. Only their own needs (and that of their often exhausted families) coupled with the desire to pursue the institution's promise of remission made individuals willing to undertake sanitarium treatment.

The biological character of particular ills helps define public health policies as well as therapeutic options. Tuberculosis provides only one sort of example. Acute ills obviously provide a very different challenge to physicians, governments, and medical institutions. But even acute infections vary in their modes of transmission, for example, and thus in their specific social identity. Attitudes toward sexuality and the need to change individual behavior, for example, constrain efforts to halt the spread of syphilis (Brandt 1985). To cite another sort of instance, water-borne ailments like typhoid or cholera could be interdicted by the skills of bacteriologist and civil engineer and the decisions of local government—without the need to alter individual habits.

I do not mean to imply that such decisions were no more than

enlightened responses to medicine's changing understanding of the transmission of such ills. Particular decisions to build new water systems reflected political alliances, economic pressures, and social perceptions—including attitudes toward the medical profession and toward infectious disease itself.

Disease as Frame

Once crystallized in the form of specific entities and seen as existing in particular individuals, disease serves as a social actor and mediator. This is an ancient truth. It would have hardly surprised a leper in the twelfth century, or a plague victim in the fourteenth. Nor, in another way, would it have surprised a "sexual invert" at the end of the nineteenth century.

These instances remind us of a number of important facts. One is the role played by laymen as well as physicians in shaping the total experience of sickness. Another is that the act of diagnosis itself becomes a key event in the experience of illness; logically related to this point is the way in which each disease is invested with a unique configuration of social characteristics—and thus triggers disease-specific attitudinal responses. Once articulated and accepted, disease entities became "actors" in a complex social situation. Finally, of course, our case studies suggest that this process is deeply embedded in human history. The nineteenth century may have changed the style and content of individual diagnoses—and expanded the conventional boundaries of illness especially in the sphere of behavior—but it did not initiate the social centrality of disease concepts and the social significance of diagnoses once made.

Michael MacDonald's (1989) study of suicide in early modern England underlines both the antiquity and negotiated quality of disease definitions; it illustrates as well the possibility of medicalizing behavior and thus changing its moral—and in the case of suicide, legal—meaning. Perhaps most strikingly, it illustrates the way in which medical personnel and formal medical thinking constituted only one factor in a diverse social and intellectual context. Suicide became increasingly a retrospective evidence of exculpatory disease—as in instance after instance ordinary Englishmen preferred that option to its legally and traditionally mandated alternative. They chose not to label their deceased family members, friends, and neighbors as crim-

inally responsible for their final act—and in doing so to forfeit their property to the state. It provides as well an instance in which behavior alone could serve as the crucial element in a “diagnosis” of “sickness.”

Certainly the circumstances surrounding suicide—the need to negotiate concrete determinations at a particular moment in time, for example, and the gradient defined by the harsh and brutal alternatives to a verdict of unsound mind—are a bit atypical. And so is the chronology; a willingness to expand the boundaries of legitimate illness so as to include behavior is more typically characteristic of the nineteenth century.

The expansion of diagnostic categories in the late nineteenth century did create a new set of putative clinical entities that seemed controversial at first, and certainly served as one variable in defining the feelings of particular individuals about themselves, and of society about those individuals. Inevitably, the controversy turned on matters of value and responsibility as well as epistemological status. Was the alcoholic a victim of sickness or of willful immorality? And if sickness, what was its somatic basis? Was the individual sexually attracted by members of the same sex simply a depraved person who chose to commit unspeakable acts, or a personality type whose behavior was in all likelihood the consequence of hereditary endowment (Weeks 1981; Hansen 1989; D’Emilio and Freedman 1988)?

It is clear that such dilemmas are not simply an incident in the intellectual history of medicine, but an important symptom of changing social values more generally—and as well, of course, a factor in the lives of particular men and women. It is equally clear that this style of social negotiation is very much alive today as physicians and society debate issues of risk and life-style, and as government and experts assess deviance and evaluate modes of social intervention. The historian can hardly decide whether the creation of such diagnoses was positive or negative, constraining or liberating, for particular individuals, but the creation of homosexuality as a medical diagnosis, for example, certainly altered the variety of options available to individuals for *framing themselves*, their behavior, its nature and meaning. It offered the possibility—for better or worse—of construing the same behaviors in a new way and of shaping a novel role for the physician in relation to that behavior (sometimes in courts or in the administrative routine of education and social welfare).

But this is not only true of such morally and ideologically charged

diagnoses. Even diseases such as cancer and tuberculosis, as we have seen, shaped individual lives in the nineteenth century—just as a late-twentieth-century diagnosis of heart disease becomes an aspect of individual personality, to be integrated in ways appropriate to personality and social circumstance. Diet and exercise, anxiety, avoidance or depression can all constitute aspects of that integration. Once diagnosed as epileptic, to cite another example, in centuries before our own—or as a sufferer from cancer or schizophrenia in our generation—an individual becomes in part that diagnosis.

The technical elucidation of somatic disease pictures could add to—or refine—the existing vocabulary of disease entities. The nineteenth century saw a host of such developments. The discovery of leukemia as a distinctive clinical entity, for example, created a new and suddenly altered identity for those individuals the microscope disclosed as incipient victims. Before that diagnostic possibility they might have felt debilitating symptoms—but symptoms to which they could not put a name. With that diagnosis, the patient becomes an actor in a suddenly altered narrative. Every new diagnostic tool has the potential for creating similar consequences—even in individuals who had felt no symptoms of illness. Mammography, for example, can suggest the presence of carcinoma in women entirely symptom free. Once that radiological suggestion is confirmed, an individual's life is irrevocably changed.

For centuries disease—both specific and generic—has played another role as well. It has helped frame debates about society and social policy; since at least Biblical times the incidence of disease has served as index and monitory comment on society. Since at least the eighteenth century, physicians and social commentators have used the difference between “normal” and extraordinary levels of sickness as an implicit indictment of pathogenic environmental circumstances. Military surgeons worried, for example, about the alarming incidence of camp and hospital disease; the frequency of death and disabling sickness in a youthful male population underlined the need for reform in existing camp and barrack arrangements. Medical men in Europe's new industrial cities pointed to the incidence of fevers and infant deaths among tenement dwellers as evidence of the need for environmental reform; the instructive and unquestioned disparity between morbidity and mortality statistics in rural as opposed to urban populations constituted, for example, a compelling case for public health

reform (cf., for example, Eyler 1979; Coleman 1982). A perceived gap between the *is* and the *ought to be* has often constituted a powerful rationale for social action.

The rich historical tradition of social medicine as implicit social criticism was built around the analysis of disease incidence. Henry Sigerist in the 1930s, for example, like many of his generation, saw disease incidence as in part a consequence of—and comment on—capitalist social relations; in his younger years, as Elizabeth Fee (1989) emphasizes, Sigerist had tended to view disease as a reflection of culture. What both of Sigerist's positions had in common was a centuries-old emphasis on the relation between particular incidences of disease and particular social realities.

But as John Eyler (1989) demonstrates in his discussion of Arthur Newsholme's thought, this style of social analysis was complex and often self-contradictory. Were individuals responsible for the behavior that placed them at risk—or were they passive victims of inimical social circumstances? Few physicians could ignore either kind of causation—and, in fact, were well aware that both factors could interact, creating “vicious cycles” of poverty, environmental deprivation, immorality, and ultimate and inevitable disease. In this sense disease became an occasion and agenda for a generation-long debate about the relation among state policy, medical responsibility, and individual culpability. It is a debate that has hardly ceased—as the recent outbreak of AIDS has so forcefully emphasized.

AIDS is more than a metaphor for something else—though like plague or cholera it is necessarily that as well. It has reminded us that infectious disease is not simply an occasion for research and clinical investigation or the blaming of victims, but potentially a matter of life and death. It is a forceful reminder that we have not banished infectious disease—as we have famine—from the developed world. Earlier generations were hardly in need of such enlightenment. Epidemic disease has been omnipresent in human history and thus fundamental in the negotiation of social values, attitudes, and individual identities. A growing academic concern in recent decades is no more than a respectful obeisance to a fundamental aspect of perceived social reality in every culture, in every time and every place.

Although we have begun to study the history of disease and have cultivated a growing appreciation of the potential significance of such studies, much remains to be done. As the following pages suggest,

the study of disease constitutes a multidimensional sampling device for the scholar concerned with the relation between social thought and social structure. Although it has been a traditional concern of physicians, antiquarians, and moralists, the study of disease in modern society is still a comparatively novel one for social scientists. It is more an agenda for future research than a repository of rich scholarly accomplishment. We need to know more about the individual experience of disease in time and place, the influence of culture on definitions of disease and of disease in the creation of culture, and the role of the state in defining and responding to disease. We need to understand the organization of the medical profession and institutional medical care as in part a response to particular patterns of disease incidence. The list could easily be extended, but its implicit burden is clear enough. Disease constitutes a fundamental substantive problem and analytical tool—not only in the history of medicine, but in the social sciences generally.

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